A Snapshot of

Adolescent and Young Adult Cancers

Cancers Affecting Adolescents and Young Adults (AYAs)

Nearly 68,400 adolescents and young adults (AYAs) aged 15-39 were diagnosed with cancer in 2009.1 This is almost six times the number of cases diagnosed in children ages 0-14. The incidence of specific cancer types varies dramatically across the AYA age continuum. For example, leukemia, lymphoma, and testicular cancer (germ cell tumors) are the most common cancer types in younger AYAs (less than 24 years old). In older AYAs (ages 25-39), by contrast, these cancers decline in frequency, and other cancers such as cervical, colorectal, and, particularly, breast cancer are more common.² See Cancers in Young People to learn more.

Incidence and Survival

Cancer is the leading cause of disease-related death in the AYA population; among females, it is the most common disease-related cause of death, and among males it is second only to heart disease.³ In the AYA age group, only accidents, suicide, and homicide claim more lives than cancer.

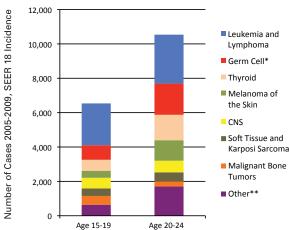
Incidence rates of cancers in AYAs vary by race and ethnicity. Rates of both cancer incidence and 5-year survival are highest among white AYAs. American Indian/Alaska Native AYAs have the lowest cancer incidence rates, but they also have poorer survival rates than whites. African Americans have intermediate incidence rates and the lowest 5-year survival rates.

Unlike improvements seen in younger and older age groups, survival rates for young people (AYAs) with cancer have not improved in almost 30 years.

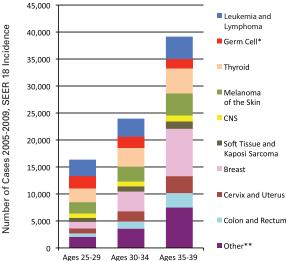
Factors that may account for the lack of improved outcomes among AYAs include:

- Delayed diagnosis of primary cancers
- Poor understanding of the biology and etiology of the cancers in this population
- Inadequate access to clinical trials and low rates of participation
- Inadequate treatment practices and settings
- Unique psychosocial and supportive care needs.
- Calculated by Surveillance, Epidemiology and End Results (SEER) Program using SEER 18, 2005-2009.
- ² Data from the SEER Program.
- and the National Center for Health Statistics.

Common Types of Cancers Affecting AYAs

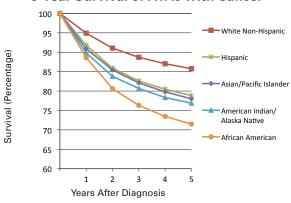


- Includes testicular cancer.
- ** Includes breast, cervix, colon, and other less prevalent cancers. Data source: SEER 18, 2005-2009, ages 15-24.



- Includes testicular cancer.
- ** Includes malignant bone tumor and other less prevalent cancers. Data source: SEER 18, 2005-2009, ages 25-39.

5-Year Survival of AYAs with Cancer



Hispanic ethnicity is independent of race and can overlap with African Americans, Asians/Pacific Islanders, or American Indians/Alaska Natives. White is limited to non-Hispanic white. Analysis was based on any death from any cancer site in both sexes and all races, ages 15-39 years. Data Source: SEER 13 Areas, 1992-2008.

Total U.S. deaths in 2009, ages 15-39, from the SEER Program

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Selected Advances in AYA Cancer Research

- Melanoma in adolescents and young adults (ages 15–39 years): United States, 1999–2006 examined the burden of melanoma among AYAs and suggested areas for etiologic research around gene-environment interactions and the need for targeted cancer control activities specific to AYAs. Published November 2011.
- Unmet adolescent and young adult cancer survivors information and service needs: a population-based cancer registry study describes unmet information and service needs of AYA cancer survivors and identifies sociodemographic and health-related factors associated with these unmet needs. Published March 2012.
- Positive and negative psychosocial impact of being diagnosed with cancer as an adolescent or young adult explores the psychosocial impact of cancer on newly diagnosed AYA cancer patients. Published March 2012.
- Impact of cancer on work and education among adolescent and young adult cancer survivors finds that although most AYA patients with cancer return to work after cancer, treatment intensity, not having insurance, and quitting work/school directly after diagnosis can influence work/educational outcomes. Published May 2012.
- So others may benefit: Young cancer patients and survivors take part in oncofertility research after learning about options through social media and a network of fertility clinics. Reported June 2012.
- Click <u>here</u> to access selected free full-text journal articles on advances in NCI-supported research relevant to adolescent and young adult cancer. Click <u>here</u> to search for additional scientific articles or to complete a <u>search tutorial</u> on PubMed.

Examples of NCI Activities Relevant to AYA Cancers

- The Adolescent and Young Adult Health Outcomes and Patient Experiences (AYA HOPE) Study is a populationbased cohort study funded by NCI with support from the Lance Armstrong Foundation. The study collected medical record and survey data from over 500 newly diagnosed AYA cancer patients with germ cell cancers, Hodgkin and non-Hodgkin lymphoma, acute lymphoblastic leukemia, or sarcoma.
- The Phase III Randomized Trial of Adding Vincristine— Topotecan—Cyclophosphamide to Standard Chemotherapy in Initial Treatment of Non-metastatic Ewing Sarcoma clinical trial is enrolling AYAs in the first Children's

- Oncology Group (COG) trial available through NCI's Cancer Trials Support Unit (CTSU). See the entry criteria and trial contact information or call NCI's Cancer Information Service at 1-800-4-CANCER (1-800-422-6237) for more information.
- The <u>Mithramycin for Children and Adults with Solid Tumors or Ewing Sarcoma</u> trial is testing the efficacy of the previously established adult dose in young adults with EWS-FL1+ Ewing sarcoma.
- Other NCI-sponsored cooperative group clinical trials for AYA include <u>CALGB-10403</u>, <u>COG-AALL1131</u>, and <u>COG-AALL0434</u> for acute lymphoblastic leukemia; <u>COG-AAML1031</u> for acute myeloid leukemia; and <u>COG-ARST08P1</u> for rhabdomyosarcoma.

Additional AYA Cancer Resources

- The <u>NCI Adolescents and Young Adults with Cancer</u>
 <u>Portal</u> provides information on AYA cancers, treatment and clinical trials, coping and support, survivorship, resources, reports, and other related topics. Information specialists also can answer questions about cancer at 1-800-4-CANCER.
- The NCI Cancer Bulletin featured a **Special Issue:** Adolescent and Young Adult Cancers.
- NCI developed the <u>Adolescent and Young Adult (AYA)</u>
 <u>Cancers Quiz</u> for the 2012 Annual National Young Adult
 Cancer Awareness Week to increase knowledge regarding
 AYA cancers.
- Focus Under Forty, a series of educational modules developed by American Society of Clinical Oncology and LIVESTRONG with input from the NCI, is designed to increase awareness and enhance the understanding of care issues and challenges associated with cancer in AYAs.
- NCI's AYA YouTube playlist includes these videos:
 - Cancer researchers, advocates, and a cancer survivor introduce the topic of AYA cancers in <u>Cancer Research</u> Now: Adolescent and Young Adult Cancers.
 - AYA cancer experts address what to tell an AYA with cancer in the video <u>In Their Own Words: After a</u> <u>Diagnosis, Adolescents and Young Adults with Cancer.</u>
 - Cancer Research Now: Fertility Issues for Adolescents and Young Adults with Cancer addresses options for preserving fertility, current research questions, and policy concerns regarding the effect of treatment on fertility, a special concern for AYA patients.
- Additional reports and research that address the challenges facing adolescents and young adults with cancer can be found at <u>Adolescents and Young Adults with Cancer:</u> <u>Reports, Research, and Literature.</u>





